Title

bigconversations: A National Survey of Anaesthetists' Preferences for their Own End of Life Care

Short Title

bigconversations: Anaesthetists' EoL Preferences

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Abstract

Objectives: To develop a valid questionnaire to describe individual views, wishes and preferences for end of life care and report UK anaesthetists personal perspectives.

Methods: The bigconversations questionnaire was developed by modifying an existing framework for end of life discussions. An online cross-sectional survey of UK anaesthetists was then conducted using the questionnaire in January 2019.

Results: The bigconversations questionnaire was validated as measuring the important aspects of end of life care by an expert panel and was found to have moderate test-retest reliability.

Responses were received from 760/1,913 (40%) of those invited to take part. 698/760 (92%) of respondents wished to be well informed about their condition and prognosis and 518/760 (68%) wanted to be heavily involved in decision making about their health. 639/760 (84%) respondents would choose to forego treatment aimed at prolonging life should that life be of poor quality. The desire to spend time with family was a theme which arose from the qualitative analysis.

Conclusion: This study provides the first systematic description of UK doctors, specifically anaesthetists, personal preferences for end of life care. Broad trends were identified: to be well informed; to avoid high-intensity medical treatments if terminally unwell; to spend remaining time with family and friends; and to be symptom free and well cared for. However, a substantial minority expressed different, indeed opposite, opinions. This variation highlights that good quality end of life care must be driven by discussion of an individual's values, wishes and preferences.

Key Words

Surveys and Questionnaires

Terminal Care

Palliative Care

Health Personnel

Communication

Introduction

In 2011, Dr Ken Murray published an essay describing a medical colleague's decision to opt for symptom relief as opposed to chemotherapy when he was diagnosed with terminal cancer[1]. The essay shared his observation that doctors seemed more likely to die at home with less aggressive care than most people received at the end of life (EoL). The essay went 'viral' and was reprinted in multiple languages in magazines and newspapers around the world[2]. More recently, surgeon Atul Gawande's '*Being Mortal*[3] and Dr Paul Kalanithi's post-humous memoir '*When Breath Becomes Air*[4] have both become international bestsellers, exploring their own mortality and that of their loved ones.

Reinforcing the views of Murray, Gawande and Kalanithi, international survey data from the US[5–14], Singapore[15] and Italy[16] all suggest that as patients, most doctors and health professionals, would choose to avoid high-intensity treatments if terminally unwell or facing a poor prognosis.

When a patient or a close family member is being asked to give an opinion on EoL wishes they are often being asked to imagine situations that sit far outside their personal understanding. Surveys of patients, surrogates and the general public have shown that survival following CPR is either greatly overestimated or completely unknown[17–22]. The view that 'doctors die differently' has become common wisdom[23] and has been reported in the UK press[24]. It has been hypothesised that this is a result of doctors' greater understanding of the limitations of modern medicine and their close-up experience of dying. However, there are little data to support this in a UK context.

Doctors' personal preferences may have influence beyond their own treatment. There is significant variation between geographic regions in the US in spending for patients in the last 6 months of life; spending being used as a proxy for 'intensity' of care at EoL[25 26]. Interestingly, differences in patient preferences do not appear to explain this variation[25]. However, in geographic areas where doctors' own preferences were for more 'aggressive' care (e.g. favouring CPR in the context of a brain injury with poor quality of life), there was higher spending for patients in the last 6 months of life and in the admission in which the patient ultimately died[26]. From these data it appears that it is doctors' as opposed to patient's personal preferences which may determine intensity of treatment.

In the UK, anaesthetists have a large role in the delivery of high-intensity treatments such as CPR, inotropic support and mechanical ventilation. Intensive Care Medicine (ICM) as a speciality continues to draw most heavily on the anaesthetic workforce with the majority of ICM doctors also being anaesthetists[27]. ~~Furthermore, the reach of anaesthesia is large. It~~ Anaesthesia is the largest in-hospital specialty and 2 in 3 in-patients will be cared for by an anaesthetist at some point during their hospital stay[28] in a variety of different settings. Recent years have seen an increasing emphasis of the role of the anaesthetist counselling patients pre-operatively[29], with these discussions offering an opportunity to explore patient preferences and expectations about high-intensity medical treatments[30].

Our aim was to develop a valid instrument to describe individual views, wishes and preferences for EoL care and report UK doctors' personal perspectives. Anaesthetists were chosen as a cohort given the size of the specialty and the frequency with which they discuss and deliver high-intensity treatments and treat critically unwell patients in a wide variety of clinical settings.

Methods

In January 2019, members of the Royal College of Anaesthetists Membership Engagement Panel (RCoA-MEP) were invited to participate in an online questionnaire via email.

We adopted a ten-question questionnaire (*bigconversations questionnaire* (Supplemental File) to describe the views of doctors towards their own EoL care.

Questionnaire Development

The study questionnaire was a modification of a 12 page document previously published by 'The Conversation Project', a US organisation dedicated to helping people talk about their wishes for EoL care[31]. The required permission was granted from Ariadne Labs for its modification and research use. Phase one of the questionnaire development took the original US document and piloted it with a group of 37 anaesthetists at a central London teaching hospital. This facilitated a consultation process about its applicability and usability in a UK healthcare setting. Phase one outcomes led to document shortening in order to improve response rate and to capture the attention of people for whom this may not be an immediate concern. A modified, anglicised, questionnaire was produced consisting of ten questions.

Eight questions adopted a five-point Likert scale, one question was multiple-choice, and one was an open-ended free-text question. The free-text question allowed respondents to expand on answers in previous questions and to raise concerns or issues that the research team had not previously considered. Ten supplementary questions enquiring about respondent demographics were also included.

Content Validity

Phase two of questionnaire development involved its content validation, using the content validity index (CVI) as recommended by Polit et al.[32]. An 11-person panel was assembled which included experts from across the UK in critical care and anaesthesia; general practice; accident and emergency; palliative care;

survey research and RCoA lay committee members. Each was asked to comment on three domains as described by Grant & Davis[33]: the relevance of each question; the clarity of each question; and the comprehensiveness of the entire questionnaire. All questions were found to have a CVI >0.78, therefore, not requiring question revision in line with the model described by Polit et al.[32]. Revisions were made to the wording of the questions to improve clarity and understanding based on feedback from the expert panel. The panel unanimously agreed that the questionnaire was comprehensive and covered the important aspects of EoL care for an individual.

Sampling

Royal College of Anaesthetists (RCoA) census data from 2015 confirmed 14,000 practicing UK anaesthetists[34] and from this number a sample was drawn using the 1,913 members of the RCoA-MEP. This group represents a diversity in professional grades, ages and gender and had previously agreed to be active participants in RCoA related engagement exercises. Whilst this was a self-selecting group, who were thought to be more likely to engage with the questionnaire than other RCoA members, we saw no reason why their views on EoL care would be different from their colleagues. The benefits of an expected higher response rate and usable contact details were felt to outweigh concerns of their representativeness.

Sample Size

A minimum sample size of 375 was required in order to provide a level of precision of +/-5% using Cochran's formula for sampling proportions in a finite population[35]. No similar type of survey had been conducted with the RCoA-MEP and therefore the expected response rate was unknown. As there was no disadvantage in terms of cost or time given this was an electronic survey, the entire sampling frame was surveyed.

Survey Administration

The study, including the questionnaire, was approved by the University College London Research Ethics Committee (study reference number: 12469/001). Methods for handling and storing data were compliant with all data protection legislation including the EU General Data Protection Regulation (GDPR)[36].

The questionnaire was administered using the online survey platform Survey Monkey. Members of the RCoA-MEP were initially contacted via an email from the RCoA inviting participation. The survey introduction page acted as a consent form and participant information sheet (Supplementary Information). It stated that consent for data being used for specified purposes was implied from participating in the survey. This complies with standard practice for most large-scale surveys such as those undertaken by government departments in the UK[37].

The survey ran for 25 days between 7/1/19 and 31/1/19 with two automated reminders sent to those who had not taken part by the 15/1/19 and 21/1/19. No financial incentives were offered to those taking part.

Analysis of non-response error

Non-response bias occurs if there is a systematic difference between those who complete the questionnaire (respondents) and those who do not (non-respondents). When this occurs, it means that conclusions drawn from the respondents may not generalise to non-respondents and by extension to the overall population[38]. The most common method to account for this is to check for similarities between respondents and known population characteristics[38–40]. Limited data about population characteristics were available from the RCoA's Medical Workforce Census Report from 2015 [34] and these were used for comparison.

In addition, wave analysis was conducted. This compares early and late responders[41] and is based on the idea of a 'continuum of resistance'[42]. This is an assumption that late respondents are 'almost' non-respondents. We can then compare late with early respondents to assess potential differences which may approximate non-response bias[43]. The sample was divided into early, middle and late responders depending on whether respondents replied to the initial email, the first reminder or the second reminder. This was assessed non-parametrically using Kruskal-Wallis one-way and Cuzick trend analyses.

Incomplete submissions / missing data

A commonly used tactic to avoid 'missing data' from online questionnaires is to employ 'forced answering'[44] which minimises, or avoids, non-response to items[45]. In this survey respondents were not forced to answer questions and could skip or leave blank as they wished. Our view was that forced answering is unethical as it coerces respondents to answer even if they wish not to. Additionally, forced answering results in poorer quality data as respondents are likely to have a good reason for choosing not to give an answer (e.g. not understanding the question; no appropriate category)[46]. The numbers of non-respondents for each question is presented with the results.

Reliability

In order to calculate the reliability, i.e. the repeatability or stability of results over time, a test-retest approach was used. Respondents were asked to retake the questionnaire 6 weeks after completion and the paired responses were used to calculate the reliability of each question using the weighted Kappa statistic[47]. The strength of agreement for a given kappa value was determined using Landis & Koch's framework[48]. The median absolute differences are presented to show the magnitude of differences between test and retest responses. Additionally, the 95% intervals of agreement are presented for the absolute differences between test and retest scores.

Data Analysis

Data were exported from Survey Monkey and analysis conducted using the R Statistical Computing language (R version 3.5.0; R Foundation for Statistical Computing, Vienna, Austria) and Number Cruncher Statistical Systems (NCSS) (version 12, NCSS Inc., Kaysville UT). Results are presented as count (%).

Statistical significance was defined at *P*<0.05 (two-sided) with Bonferroni corrections for multiple comparisons and 99.4% confidence limits (CL) for median absolute differences to keep the overall type I error at <5% as appropriate.

Analysis of free text qualitative answers

Free text qualitative answers were compiled in a single list and were left unedited (no corrections for spelling or grammar). Data were analysed using thematic analysis[49] to allow for the identification of patterns across the data set. A broadly descriptive type of thematic analysis was employed when developing the themes. Data were read numerous times to ensure immersion with initial notes of potentially interesting aspects made. Following from this the entire data set was coded by author DB. Codes were derived from the data capturing descriptive elements e.g. "I don't want to be in pain" was coded "pain free". A review of the coding of the dataset, including the codes used, was performed by author CVP and the dataset was then reread and recoded with codes added, modified or removed as required to ensure consistency. Potential themes were identified with relevant data collected under each theme and reread to ensure the themes appropriately captured the views and beliefs of respondents.

Results

1,913 members of the RCoA membership panel were sampled by email and 760 (40%) completed the questionnaire. When answering the qualitative free-text question, 688 (91%) respondents provided at least one useable answer, 664 (87%) provided two and 612 (81%) provided three. This resulted in a total of 1,964 free text answers available for analysis. The main themes which emerged are presented in Table 3.

61% of those who responded were male and the vast majority (95%) were between the ages of 25-64. Most (96%) described their health to be 'good' or 'very good' and were not limited in their day-to-day activities (91%). 21% had caring responsibilities for others because of ill health or disability. 56% were white. 41% identified as Christian and 37% percent held no religious belief. Table 1 presents an overview of the demographic and personal characteristics of respondents.

Non-Response Error

The 2015 RCoA's Medical Workforce Census Report estimates that around 68% identify as male compared to 61% (95% CI 57-64%) of our respondents. It also estimates that around 53% are Consultants compared to 60% (95% CI 57-64%) of our respondents.

Respondents were divided into three *waves* to allow for wave analysis: early responders (n = 485), middle responders (n = 285) and late responders (n = 33). The Bonferroni corrected alpha level representing significance was calculated as <0.00625. No statistically significant difference was detected between the waves at the Bonferroni corrected alpha level. Only Q6 had an uncorrected *P* value <0.05 for both the Kruskal-Wallis and Cuzick trend analyses. Based on these results there is little evidence of systematic differences between early, middle and late responders.

Reliability

The reliability of the questions, as calculated using the weighted Kappa statistic, are presented in Table 2. One question had substantial, seven moderate and one a fair level of agreement when assessed using weighted Kappa. The median size of any change between test and retest scores was at most one out of five categories even at the 95%CL. The 95% intervals of agreement showed that 95% of raters differed by no more than 2 categories at most. These are also presented in Table 2.

Patient Engagement

The level of ‘patient engagement’ was measured in Q1, Q2 and Q3 (Figure 1) with most respondents favouring a high level of input. Ninety two percent of respondents wished to be well informed about their condition and prognosis and sixty eight percent wanted to be heavily involved in decision making about their health. A desire for autonomy and control over decision making was a major topic of the qualitative analysis with a particular focus on medical decision making (Table 3).

Intensity of Treatment

The intensity of treatment at EoL was explored in Q4, Q5 and Q9 (Figure 2). Most respondents (84%) would choose to forego treatment aimed at prolonging life should that life be of poor quality and many (49%) would avoid treatments which may prolong life at the expense of discomfort. Our qualitative analysis (Table 3) found concern about the undertreatment of pain and a desire for adequate symptom control (including of nausea and respiratory distress) and to pursue ‘quality’ over ‘quantity’ of life. A wish to avoid the ‘medicalisation’ of death was reflected in both the free-text comments and in Q9 where the desire of most respondents (91%) was to avoid hospital as a place to die.

Role of Family and Friends

The role desired of family and friends was explored in Q6, Q7 and Q8 (Figure 3). The desire to spend time with family was a theme which arose from the qualitative analysis (Table 3) and this was consistent with responses to Q7. Free-text comments illustrated a concern over what effect the respondents' death would have on family and friends. Q6 showed that most (67%) would still wish for family and friends to follow their wishes regarding medical treatments even if it made them uncomfortable. Most (64%) would be happy to share information about their health and illness with family and friends.

Discussion

The ‘bigconversations’ questionnaire has been developed and validated, allowing the description of views, wishes and preferences for EoL care. It is the first study describing UK doctors’ own priorities for EoL care. Whilst we detail the most prominent and common views, in our opinion, the most interesting finding of this study is the variation of views that respondents have shown. There are undoubtedly broad trends: to be well informed; to avoid high-intensity medical treatments if terminally unwell; to spend remaining time with family and friends; and to be symptom free and well cared for. However, it is crucial to recognise that a substantial minority expressed different, indeed opposite, opinions. Some respondents would choose to be given minimal information and would prefer to delegate decision making to their healthcare team or family. For some, *‘quantity’ is* more important than *‘quality’* and discomfort is a price worth paying in order to prolong life. Whilst a concern about overtreatment was more prevalent, others worried that they would not be offered potentially lifesaving, or life-prolonging, treatments.

Both the quantitative questions and the qualitative analysis have highlighted a desire for autonomy and control over medical decision making. It has been postulated that, in contrast to patients and families, doctors’ views of a good death are primarily ‘biomedical’ in nature[50]. However, it would be wrong to suggest there is a large gulf between doctors and members of the public. Similar to our findings, the majority of patients and members of the public do report that they would want to be provided with information about diagnosis, treatments and life expectancy[51–56]. What is less clear is whether patients and the public desire the same level of control over decision making as the doctors we have surveyed.

The intensity of treatment desired by both healthcare professionals and members of the public is well described internationally. Previous studies in North America[5–14], Europe[16] and Asia[15] have shown that healthcare professionals would choose to avoid high-intensity treatments should they be terminally unwell. This is consistent with our findings amongst UK doctors. The majority of members of the public similarly report that they would prefer quality over quantity of life[56 59] and that avoiding inappropriately prolonging death is a key component of good EoL care[53 60]. This suggests that the views of healthcare professionals and the public are broadly similar. One study comparing medical students at different stages of training found that after two years of training, students reached similar rates of refusal of 'aggressive' treatments as practicing doctors [7]. Given that our cohort of UK anaesthetists have a large exposure to high-intensity treatments such as CPR and mechanical ventilation, it is consistent that they would be more likely to refuse such treatments if terminally unwell.

In our study, hospital was the least popular place in which people would choose to die, with hospice being favoured by almost 2/3. These preferences are similar, but more pronounced, than those of members of the public. Members of the public mostly want to avoid dying in hospital, but a home death is more heavily favoured[51 54 56 61–63]. This may reflect an awareness, amongst our respondents, of the high care requirements that dying patients have, which may not be able to be met at home. Alternatively, given that the majority of these studies are from outside the UK, it may represent the greater prevalence and role of the hospice movement in the UK[64].

An interesting contrast within our findings arose when considering the role of family and friends. A major theme of the qualitative analysis was of the importance of family and friends: a desire to spend time with them, to avoid causing them suffering and to not become a burden to them. Despite this, few wish to relinquish decision making should they disagree about medical treatments. For some, the desire for control and autonomy appears to be prized so highly that respondents are willing to tolerate the discomfort of family and friends in order to maintain it. In comparison, a Canadian study of patients with advanced chronic kidney disease found that 89% would want family/friends to make medical decisions for them should they lose capacity[54].

The qualitative analysis has allowed a much greater depth of understanding than could have been garnered from a quantitative questionnaire alone. A major finding in our qualitative analysis was of the point of transition between curative and palliative treatments. The loss of physical or mental capabilities was often mentioned as the marker of when this transition should occur.

Two additional aspects which arose from the qualitative analysis were of the importance of 'care' and the desire to make plans for 'after death'. Care in this context is quite separate from treatment and revolves around the protection from harms and the importance of "respect", "dignity" and "compassion" from healthcare professionals. A harm which respondents desired protection from was the symptoms associated with dying. Concern about the undertreatment of pain is consistent across surveys of healthcare professionals[14 50], members of the public[56 59 60 65–68] and recently bereaved family members[10] and was similarly a significant finding in our qualitative analysis. Plans for 'after death' included medical concerns such as organ donation as well as funeral plans, financial and estate issues and caring responsibilities for other family members. These concerns have been highlighted as important in previous studies[10 53 59], with the exception of organ donation. Organ donation was particularly prominent in our free-text answers and this likely represents a nuance of our medical cohort. The idea of 'life completion'[57] and 'a feeling of closure'[58] have previously been described as important aspects of EoL care. Our qualitative analysis did find references to 'saying goodbye' and 'acceptance of dying', however, this idea of 'completion' did not emerge as a major theme in our study.

The first 'Ambition for Palliative and End of Life Care'[69] is that each person is seen as an individual and has access to person centred care that allows them to take control at the end of their life. That variation exists in a relatively homogenous sample consisting solely of anaesthetists shows there is no single definition of a 'good death'. Good quality EoL care must be a process which is driven by discussion of an individual's values, knowledge and preferences. When considering high-intensity treatments this discussion will likely benefit from input from those with knowledge and experience. Given that clinicians own preferences have been shown to influence care for patients[25 26] there is a risk that patients may be ‘directed’ towards a decision they would not have made for themselves. This concern must be balanced so it does not prevent guidance from being given to patients by those who understand the realities of high-intensity treatments. A potential solution would be to use information about clinicians’ views to provide ‘balanced’ teams ensuring patients have access to multiple perspectives. Practically this may be difficult given time, resource and rota constraints. Early discussions with multiple clinicians over the months and years prior to acute illness may be a more pragmatic solution and allow patients access to different perspectives. These could take place in GP consultations, medical specialties outpatient appointments or perioperative reviews prior to elective care. A systematic review found over 70% of patients’ EoL preferences are stable over time with greater stability if they have engaged in advance care planning[70]. Repeated conversations over time should allow patients to develop stable views which reflect their values and preferences as well as allowing for those who may change their mind to do so.

This study must be considered with its strengths and weaknesses in mind. The response rate was 40%. This is actually slightly higher than the average of ~34% for online surveys involving the general population[71] and in keeping with an average response rate of ~38% for online surveys involving healthcare professionals[72]. There is always a concern when conducting survey research of non-response bias. In an attempt to address this, we compared respondents’ characteristics with known population characteristics. This comparison suggested that the sample underrepresented males and overrepresented Consultants. This may reflect actual differences between the sample and population. However, it may also represent a changing workforce since 2015, which is increasingly female and comprised of Consultants. Wave analysis was also performed which did not reveal a difference between the answers of early, middle or late responders. The questionnaire made no mention of functional status, co-morbidities or quality of life. It is likely that these factors would have a large impact on decision-making. A survey of US doctors found that there was declining accession to undergo CPR with increasing age and pre-existing co-morbidities, particularly Alzheimer's disease[9]. There is often also a great deal of uncertainty about prognosis and therefore the likelihood of benefit of treatment to the patient[73–78]. It was a necessary constraint of our study, and similar work involving both healthcare professionals[5–9 11–13 15 16] and members of the public[52 54–56 59 61–63 65 68 79], that the scenario clearly explains that the patient is dying. The complexities of real life can rarely be captured in such a one- or two-line narrative. In future, rather than focus on whether individuals would accede to treatments in such manufactured circumstances, it may be more useful to focus on what factors would influence their decision to transition from curative to palliative treatment.

We have presented information about respondent demographics including religion, ethnicity, grade, health status and caring responsibilities. Whilst, these factors are likely to have influence on respondents' beliefs we were not able to perform a comparative analysis to assess this as to do so would have required a much larger sample size.

The calculation of reliability found that one question had substantial, seven moderate and one a fair level of agreement when assessed using weighted kappa. A partial explanation for Q1 showing only a fair level of agreement is the sensitivity that kappa has for distributional skew[80]. When responses cluster in one category, as evidenced in Q1 where 76% were in a single category, kappa decreases even if there is high agreement between test and retest responses. The calculation of median differences allowed a quantification of the size of the changes between test and retest responses and the size of the median change was at most 1 even at the 95%CL. This shows that respondents' results were relatively consistent using the questionnaire and that there was not widespread misreading or misunderstanding.

Accepting these limitations, the findings deserve attention. This study was national in scope and had a large sample size. It is the first study to look at UK doctors' personal preferences for EoL care and the addition of a qualitative free-text question has provided greater depth to the findings. The validation of the 'bigconversations' questionnaire will allow for future work to explore different groups including different medical specialties/professions and the general public. The use of this questionnaire will allow for comparative analysis between these groups.

Conclusions

This study provides the first systematic description of UK doctors, specifically anaesthetists, personal preferences for EoL care. The findings support previous work suggesting that those who have experience of high-intensity medical treatments may choose to avoid these themselves. However, even within this population there remains a spectrum of opinion further emphasising the importance of personalising EoL care and engaging in early discussion about values, wishes and preferences prior to acute deterioration and loss of capacity. The qualitative component has provided significant additional insight. It reiterated the importance of patient engagement, treatment intensity and the role of family and friends as key components of EoL care. It also highlighted new themes such as the transition between palliative and curative treatments, the importance of care, as distinct from treatment, and after death planning.

Author’s Contributions

Conception and design of study – DB, DW, MM, CVP

Data Collection – DB, DW (supervision)

Data Analysis – DB, MC

Interpretation of results – All authors

First draft of manuscript – DB

Critical revision of manuscript – all authors

All authors read and approved the final manuscript.

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Declaration of Interests

MM is on the editorial board of the *British Journal of Anaesthesia* (BJA); editorial board of Critical Care; founding editor-in-chief of Perioperative medicine; an elected council member of the Royal College of Anaesthetists; director of Evidence Based Medicine community interest company; co-director of the Duke-UCL Morpheus Consortium.

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Tables

Table 1 Demographic and professional profile of respondents to bigconversations questionnaire

	n = 760
What is your sex?	
Male	461 (60.9%)
Female	296 (39.1%)
No Answer	3
What is your age?	
0-24	11 (1.5%)
25-44	384 (50.7%)

45-64	336 (44.4%)
65-74	19 (2.5%)
75+	7 (0.9%)
No Answer	3
Are you currently practicing in the UK?	
Yes	688 (90.8%)
No	70 (9.2%)
No Answer	2
In what specialty (specialties) do you work?	
Anaesthesia	385 (50.7%)
Anaesthesia & Intensive Care Medicine	166 (21.9%)
Anaesthesia, Intensive Care Medicine & Perioperative Medicine	44 (5.8%)
Anaesthesia & Perioperative Medicine	40 (5.3%)
Other	37 (4.9%)
Intensive Care Medicine	33 (4.3%)
Anaesthesia & Pain Medicine	21 (2.8%)
Anaesthesia, Intensive Care Medicine, Perioperative Medicine & Pain Medicine	14 (1.8%)
Pain Medicine	6 (0.8%)
Anaesthesia & Other	5 (0.7%)
Anaesthesia, Intensive Care Medicine & Pain Medicine	4 (0.5%)
Intensive Care Medicine & Perioperative Medicine	2 (0.3%)
Perioperative Medicine & Pain Medicine	1 (0.1%)
Perioperative Medicine	1 (0.1%)
No Answer	1
What grade is your current post?	
Consultant	457 (60.6%)
Trainee	224 (29.7%)
SAS	54 (7.2%)
Other	19 (2.5%)
No Answer	6
How is your health in general?	
Very Good	453 (59.6%)
Good	278 (36.6%)
Fair	27 (3.6%)
Bad	2 (0.3%)
Are your day-to-day activities limited because of a health problem or disability which as lasted, or is expected to last, at least 12 months?	
Yes, limited a lot	5 (0.7%)
Yes, limited a little	61 (8.0%)
No	693 (91.3%)
No Answer	1
Do you look after, or give any help or support to family members, friends, neighbours or others because of either; long term physical or mental ill-health / disability or problems related to old age?	

No	602 (79.2%)
Yes, 1-19 hours per week	145 (19.1%)
Yes, 20-49 hours per week	9 (1.2%)
Yes, 50 or more hours per week	4 (0.5%)
What is your ethnic group?	
White - Scottish / English / Welsh / Northern Irish / British	428 (56.4%)
Asian / Asian British – Indian	117 (15.4%)
White - Any other white background	62 (8.2%)
Other	26 (3.4%)
White – Irish	21 (2.8%)
Asian / Asian British – Chinese	18 (2.4%)
Asian / Asian British - Any other Asian background	17 (2.2%)
Asian / Asian British – Pakistani	14 (1.8%)
Arab	13 (1.7%)
Black / African / Caribbean / Black British – African	12 (1.6%)
Mixed - Multiple ethnic groups - White & Asian	9 (1.2%)
Mixed - Multiple ethnic groups - Any other mixed / Multiple ethnic background	8 (1.1%)
Black / African / Caribbean / Black British - Caribbean	6 (0.8%)
Mixed - Multiple ethnic groups - White & Black African	4 (0.5%)
Mixed - Multiple ethnic groups - White & Black Caribbean	3 (0.4%)
Asian / Asian British – Bangladeshi	1 (0.1%)
No Answer	1
What is your religion?	
Christian	315 (41.6%)
No Religion	284 (37.5%)
Hindu	86 (11.4%)
Muslim	38 (5.0%)
Other	16 (2.1%)
Buddhist	13 (1.7%)
Jewish	4 (0.5%)
Sikh	1 (0.1%)
No Answer	3

Table 2 Test-retest reliability of bigconversations questionnaire

Item	Kappa	Strength of Agreement	Median Absolute Difference (99.4% CL)	95% Agreement Limits
1. I would like to know …	0.31	Fair	0 (0 to 0)	2
2. As my healthcare team treat me I would like …	0.58	Moderate	0 (0 to 1)	2
3. If I had an illness from which I were going to die, I would want to …	0.49	Moderate	0 (0 to 0)	2
4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	0.49	Moderate	0 (0 to 0)	2
5. If I had an illness from which I were going to die, I would …	0.50	Moderate	1 (1 to 1)	2
6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	0.63	Substantial	0 (0 to 1)	2
7. In the final period of time before I die, I would ...	0.59	Moderate	0 (0 to 1)	2
8. When it comes to sharing information, I want my family and / or friends to know ...	0.52	Moderate	0 (0 to 1)	2

Table 3 Main qualitative findings

Themes	Main issues mentioned in each theme	Illustrative quotations
Decision making	Maintaining autonomy and control.	“as long as I am able to make decisions, the decisions are mine and I want you to respect them and support me”
	Intensity of treatment and transition point to move towards palliative treatment Often focussed on particular medical treatments.	“not to have treatment which would leave me disabled”
	Desire for honesty and communication to aid decision making.	“I would want my healthcare team to be honest and direct with me …”
	Others who should make decisions should the respondent by incapacitated.	“I would want my wife to be kept fully informed and her views to be taken as if my own if I was not able to communicate”
	Decisions after death such as organ donation and funeral arrangements.	“I would want organ donation to be considered”
Care	How the respondent should be acted towards.	“I am still a person with emotions and feelings, and want to be treated with dignity, kindness and respectfully”
	Symptom relief. Avoidance of pain, nausea and respiratory distress.	“symptom control over everything else”.
Family and friends	Desire to spend remaining time with family and friends.	“I would prefer to spend meaningful time with people I love rather than prolong life but be unable to be myself around my loved ones”
	Concern about the impact of death and dying on their family and friends.	“I don’t want them to see me suffer”
	Avoidance of being a burden.	“I want my children’s needs to be put first. I would like them to remember me as I am. If that means dying earlier so be it.”
	Religious and spiritual beliefs.	“my faith is important to me and means death can be something to look forward to”